# ORIGINAL COMMUNICATIONS

# COMPLIANCE WITH PUBLIC SECTOR HIV MEDICAL CARE

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**Despite the availability of free or low-cost public sector human immunodeficiency virus (HIV) health-care services, important inequities in utilization exist. This study examined two measures of compliance with HIV medical care: attendance of scheduled outpatient visits and use of the emergency room. Clients of two public HIV outpatient clinics were followed from time of health-care initiation to either death or the end of the study. The association of race, sex, age, and injection drug use (IDU) with these measures were examined in multivariate logistic regression. Models were adjusted for disease staging at time of entry and for length of follow-up time in clinic.**

**Of 1824 clients followed, 15% failed to attend scheduled visits and 18.1% had at least one emergency room visit. Clients who missed visits were more likely to be African American, to have a history of IDU, and to have a $CD_4$ cell count $<500/mm^3$ or an acquired immunodeficiency syndrome (AIDS)-defining opportunistic infection at entry. They were also more likely to have $\geq$12 months of follow-up time in the HIV clinic, but were less likely to have entered into health care from an early intervention clinic. Clients who had at least one emergency room visit were more likely to be African American, female, IDU, and under 22 years of age; these clients were also more likely to have entered with $CD_4$ $<200/mm^3$ or with an opportunistic infection, and to have $\geq$12 months of follow-up in the clinic.**

**Removing the financial constraints of HIV medical care alone is not sufficient to reduce barriers to HIV health care and to improve compliance. Innovative approaches for improving access and promoting compliance with HIV medical care by African Americans and by IDUs are needed. A deteriorating immune system is associated with lesser ability to attend scheduled visits. Home care and hospice options should be considered for severely immunocompromised clients. (*J Natl Med Assoc.* 1995;87:19-24.)**

**Key words** • human immunodeficiency virus (HIV) • care utilization • compliance

Early intervention and prompt treatment of opportunistic infections have been associated with improved survival and a reduction in the number of more costly emergency room visits and inpatient stays for patients with the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS).[1-16] For example, prophylaxis against *Pneumocystis carinii* pneumonia and the use of antiretroviral therapy has been shown to reduce morbidity and prolong survival.[2-16]

Because of these findings, priority federal funding via the Ryan White CARE Act has been allocated for the provision of ambulatory care services to HIV-infected persons. These services were established to improve access to care, especially for those who might otherwise not be able to receive these services.[17] Despite the availability of these services, important differences in utilization of HIV health-care services appear to exist.

Several studies have demonstrated differences in utilization patterns by race, gender, and injection drug

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**TABLE 1. CHARACTERISTICS OF THE COHORT BY RACE (N = 1824)**

| | % African American (n = 1048) | % White (n = 776) | *P* Value |
|---|---|---|---|
| Sex | | | |
| Women | 29.4 | 8.4 | .001 |
| Men | 70.6 | 91.6 | |
| Injection drug use | | | |
| Yes | 28.7 | 24.9 | .07 |
| No | 71.3 | 75.1 | |
| Age | | | |
| <22 years | 10.1 | 2.6 | .001 |
| ≥22 years | 89.9 | 97.4 | |
| $CD_4$ count | | | |
| <100 | 23.5 | 19.5 | .15 |
| 100 to 199 | 9.4 | 11.3 | |
| 200 to 499 | 33.8 | 35.7 | |
| 500+ | 33.3 | 33.5 | |
| Opportunistic infection at entry* | | | |
| Yes | 21.5 | 21.6 | .92 |
| No | 78.5 | 78.4 | |
| Area of recruitment | | | |
| Prenatal | 5.9 | 0.9 | .001 |
| Early intervention | 14.9 | 49.1 | |
| Ambulatory care | 62.2 | 34.7 | |
| Inpatient | 17.0 | 15.3 | |
| Length of follow-up | | | |
| ≥12 months | 45.4 | 38.4 | .01 |
| <12 months | 54.6 | 61.6 | |
| ≥1 inpatient stay | 17.7 | 11.2 | .001 |
| ≥1 emergency room visit | 22.5 | 12.1 | .0001 |
| Missed scheduled visits | 17.7 | 11.2 | .001 |

*AIDS-defining opportunistic infection using the Centers for Disease Control's 1987 definition.

use (IDU) status. Mor et al[18] found that white, male, and non-IDU clients had higher rates of outpatient visits whereas nonwhite, female, and IDU clients have higher rates of emergency room use after adjusting for disease staging. Piette et al[19] reported that both HIV inpatient and outpatient service use increased over progressively lower levels of $CD_4$ counts and that nonwhites are more likely than whites to be admitted to the hospital after adjusting for clinical status but are less likely to use outpatient care. Solomon et al[20] showed that the most important predictor of inpatient and outpatient use among injection drug users was the presence of two or more HIV-related clinical symptoms after adjusting for $CD_4$ cell counts.

While these studies have provided useful information on utilization patterns, crude number of visits as a measure of care utilization has some bias. The number of outpatient visits could be linked to exogenous factors such as enrollment in a clinical trial (artificially inflating the number of visits) or inability to accommodate all visits the client wishes to make (artificially reducing the number). Using an attendance rate as the outcome measure adjusts for these factors. Use of the emergency room for visits that did not lead to hospitalization could be avoided if clients used the outpatient clinics. Nonhospitalization emergency room visits, therefore, are another indicator of lack of compliance with HIV medical care. The purpose of this study was to examine the association of race and other demographic characteristics with failure to comply with scheduled outpatient visits and with at least one emergency room visit that did not lead to hospitalization.

## METHODS

Two sites were chosen for this study: an ambulatory care clinic and an early intervention clinic. The Medical Center of Louisiana at New Orleans HIV outpatient clinic (HOP) is a state-funded urban clinic serving a largely indigent population of more than 2800 HIV-infected adults. The NOAIDS Task Force is an HIV early intervention clinic serving over 1000 clients. Clients are referred to either of these sites from any of the 30 testing sites located throughout New Orleans, the prenatal clinic, or the emergency room of the medical center.

All women, African Americans, and a random sample of white male clients of the two sites who entered into care from January 1991 to January 1994 and who had at least two visits to either clinic comprised the study population. Hispanics and Asians were excluded because they constituted less than 4% of the clientele. Clients who were receiving home-based health care during the study period were excluded (n = 29). Subjects were followed from entry to either death or the end of the study period (ie, May 1994). Clinical and care utilization information was abstracted every 6 months from the medical records of these clients and the patient charge slips.

Visits were scheduled according to the HOP and NOAIDS algorithms for subsequent visits depending on the client's $CD_4$ cell count. These are based on the recommendations of the National Institute of Allergy and Infectious Diseases consensus panel.[21] Clients of HOP with $CD_4/mm^3$ ≥500, 200 to 499, 100 to 199, and <100 were scheduled for one, two, three, and six visits,

respectively, within 6 months. Clients of NOAIDS with $CD_4/mm^3$ >600 and 350 to 600 were scheduled for one and two visits, respectively, within 6 months; patients with $CD_4mm^3$ <350 were referred to HOP. Attendance rates were determined by calculating the number of visits the clients should have attended (given the person's $CD_4$ count and the person-months of follow-up the client provided to the study). The number of actual visits the client made was divided by the ideal. Clients who actually made more visits than the basic requirement were given an attendance rate of 100%.

Clients who missed the visit on the scheduled day, but made a visit some time within the 6-month observation period were considered to have attended the visit. This criterion was used because of the clinic's policy to accommodate all missed visits by rescheduling the visit as soon as possible. In addition to the outpatient attendance rate, the number of emergency room visits the client made during the follow-up time that did not lead to hospitalization also were counted.

## RESULTS

The study sample of 1824 was comprised of 20.4% women and 79.6% men; 57.5% African Americans and 42.5% whites had a history of IDU. The mean age was 33.3 years, mean $CD_4$ cell count was $392/mm^3$, and mean time of follow-up was 11 months. At time of entry, 21.5% had a 1987 AIDS-defining opportunistic infection and 32.1% entered with $CD_4$ <$200/mm^3$.

Of the four sites of accrual into public sector HIV health care, 50.5% entered into HOP directly from screening sites, self-referral, or outside referral; 16.3% entered into HOP through the inpatient unit; 3.8% entered into HOP through the public prenatal clinic; and 29.4% entered into care through the NOAIDS early intervention clinic.

African Americans were compared with whites to determine race differences for the predictor variables. African Americans were more likely than whites to be female and under the age of 22 years; they also were more likely to have entered care through the HOP or prenatal clinic rather than inpatient or NOAIDS and to have ≥12 months of follow-up. African Americans were clinically similar to whites with respect to entry $CD_4$ cell counts and the presence of opportunistic infections (Table 1).

Fifteen percent of the total study group failed to attend the scheduled visits, 18.1% had at least one emergency room visit, and 31.3% had at least one inpatient stay. Factors associated with failure to attend scheduled visits in multivariate analyses were African-American race, IDU, entry $CD_4$ cell count <$100/mm^3$, $CD_4$ 100 to $199/mm^3$, $CD_4$ 200 to $499/mm^3$, entry with an opportunistic infection, ≥12 months of follow-up time, and entry via the inpatient versus entry via the ambulatory care unit (Table 2).

Factors associated with one or more emergency room visits in multivariate analysis were African-American race, women, IDU, <22 years of age, $CD_4$ cell count <$100/mm^3$ and 100 to $199/mm^3$, the presence of an opportunistic infection, and follow-up time ≥12 months (Table 2).

## DISCUSSION

The findings that African Americans are more likely to miss visits suggests that they are not receiving early intervention services and consequently are at risk for decreased survival and higher mortality. African Americans are a growing cohort of HIV-infected persons. Although African Americans comprised only 12% of the US population in the 1980, they represent 31.4% of all AIDS cases in 1993.[22] The findings that African Americans are more likely to use the emergency room, which is more costly than ambulatory care, implies that the overall cost of HIV care will increase.

The public health impetus to remove cost barriers has made early HIV health care financially accessible to all sociodemographic groups, but more innovative approaches are needed to make early HIV care culturally acceptable to these groups. Russell[23] states that predominant barriers to general health care for African Americans include inability to pay for services, lack of transportation and child care, and treatment and health plans that are difficult to incorporate into daily living.

Delivery of HIV care is even more complex than general health care because of the stigma attached to HIV-infected persons, which potentially isolates individuals from their support structure. Denial of the HIV infection and of the potential for death as well as fear of disclosure of HIV status is common. Traditionally, African Americans have used the emergency room for health care and have been found to mistrust institutionalized care.[24] Techniques to reduce barriers must take these phenomena into account and devise culturally appropriate methods.

Several culturally acceptable approaches to improving access have been used. At HOP, it was discovered that the percentage of missed visits was high among women, and a survey was conducted. In response to suggestions by the clients, a maternal-child program was created by offering free on-site child care, by merging child and mother visits, and by offering more

**TABLE 2. RELATIVE RISKS (RR) AND 95% CONFIDENCE INTERVALS (CI) FOR FACTORS ASSOCIATED WITH NONCOMPLIANCE WITH SCHEDULED VISITS AND WITH AT LEAST ONE EMERGENCY ROOM VISIT (N = 1824)**

| Characteristic | Did Not Attend Scheduled Visits | | ≥1 Emergency Room Visit | |
|---|---|---|---|---|
| | % | RR (95% CI) | % | RR (95% CI) |
| Race | | | | |
| African American | 17.7 | 1.7 (1.2, 2.4)* | 22.5 | 1.8 (1.3, 2.4)* |
| White | 11.2 | | 12.1 | |
| Sex | | | | |
| Women | 11.8 | 0.8 (0.5, 1.2) | 25.2 | 1.8 (1.3, 2.4)* |
| Men | 15.8 | | 16.3 | |
| Injection drug use | | | | |
| Yes | 20.2 | 1.5 (1.1, 2.0)* | 24.1 | 1.7 (1.3, 2.3)* |
| No | 13.0 | | 15.9 | |
| Age (years) | | | | |
| <22 | 7.1 | 0.7 (0.3, 1.5) | 23.0 | 1.7 (1.0, 2.7)* |
| ≥22 | 15.5 | | 17.7 | |
| $CD_4$ count | | | | |
| <100 | 33.1 | 4.4 (2.6, 7.3)* | 27.8 | 3.3 (2.2, 5.0)* |
| 100 to 199 | 21.4 | 3.3 (1.9, 5.7)* | 20.3 | 2.0 (1.3, 3.3)* |
| 200 to 499 | 11.1 | 1.9 (1.2, 3.1)* | 14.3 | 1.3 (0.9, 1.9) |
| 500+ | 5.3 | | 11.7 | |
| Opportunistic infection at entry† | | | | |
| Yes | 36.9 | 2.6 (1.8, 3.7)* | 33.6 | 1.9 (1.4, 2.7)* |
| No | 8.9 | | 13.8 | |
| ≥1 inpatient stay | 27.0 | 1.2 (0.9, 1.7) | — | — |
| No inpatient stay | 9.5 | | | |
| Area of recruitment | | | | |
| Prenatal | 8.7 | 1.1 (0.4, 2.9) | — | — |
| NOAIDS/early intervention | 4.5 | 0.9 (0.5, 1.6) | — | — |
| Inpatient | 29.0 | 1.5 (1.1, 2.2)* | — | — |
| Ambulatory care | 17.0 | — | — | — |
| Time | | | | |
| ≥12 months | 24.2 | 4.1 (2.9, 5.6)* | 26.2 | 2.5 (1.9, 3.2)* |
| <12 months | 8.2 | | 12.1 | |

*$P<.01$.
†AIDS-defining opportunistic infection using the Centers for Disease Control's 1987 definition.

private and specialized care to women. After this was implemented in January 1991, the percentage of missed visits by women decreased significantly. This may be the reason why no gender difference was found as in other studies.[18,19]

Other techniques such as the inclusion of family members in the client's care plan also may help improve access. It is also possible that African Americans do not trust institutional care and are using informal health-care systems. A national study showed that 87% of African Americans reported using an informal social network in dealing with a personal health problem.[25] In addition, many of the HIV-infected women have affected children who are not infected, and these children need to be considered in the care plan. It is essential that the client be considered as a member of a whole social network and not just a sole entity.

Injection drug users are also less likely to receive HIV early care, indicating they may be at risk for decreased survival. In addition, failure to receive early care will translate into increased need for tertiary care. Seage et al[26] demonstrated that injection drug users with AIDS had a 42% longer length of stay and a 38% higher cost per hospitalization than non-IDU AIDS patients. The number of HIV-infected injection drug users continues to grow. It has been estimated that IDU or IDU associated with bisexual and homosexual practices is responsible for more than 30% of the total number of AIDS cases.[20] If opportunistic infections can be prevented or treated earlier, more costly hospitalization can be avoided, and less costly hospice and home health can be instituted in later disease. Promoting

compliance among injection drug users is important for improving survival as well as reducing public health-care costs.

In this study, more severely immunocompromised clients were more likely to miss their visits, even after controlling for hospitalization. While information on why the clients missed the visits was not available, the apparent inability of severely immunosuppressed clients to adhere to scheduled visits suggests a greater need for hospice and home-based health care. Present eligibility for home-based care includes requirements that the client be in need of skilled service at home, be homebound, and that available resources are less than $4000, as outlined by Medicaid. Present eligibility criteria for home-based care may be too strict or the criteria for available resources may be too stringent for multiperson households. Medicaid may consider adapting guidelines according to immune status. It is essential that health-care providers consider referring clients to home-based care as they become more immunocompromised.

One limitation of the study is that those who missed visits may be receiving care elsewhere. It has been estimated that 40% of the clients used outside providers at some point during their care (S. Troxler. June 15, 1994. Unpublished data). While no statistics exist for which demographic groups are using outside providers, because African Americans are more than 2.5 times more likely to be uninsured than whites,[27] it is likely that the insured whites are the clients who are using multiple providers. If this is true, our estimates of racial differences are underestimated, and the risk for poor attendance and emergency room use is actually higher than shown in Table 2.

## CONCLUSION

Removing the financial constraints of HIV medical care alone is insufficient to reduce barriers to seeking HIV health care and improve compliance with HIV medical care. Innovative, culturally acceptable approaches for improving access and promoting compliance with HIV medical care by African Americans and for injection drug users are needed. As clients become more immunocompromised, home care and hospice care should be given more consideration.

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